

Trisomy 13 and 18 Collaborative

2026 REQUEST FOR PROPOSAL: IMPROVING CLINICAL CARE AND EXPERIENCES FOR FAMILIES IMPACTED BY TRISOMY 13 OR 18

The Trisomy 13 and 18 Collaborative is pleased to invite research teams to submit letters of intent (LOI) and, if invited, proposals to carry out research that will improve clinical care and experiences for families and children impacted by trisomy 13 or 18. The research approaches can range from data collection studies to dissemination and implementation projects, informed by family experiences and needs.

INITIATIVE OVERVIEW

The Trisomy 13 and 18 Collaborative (“The Collaborative”) envisions a health care environment where families impacted by trisomy 13 and 18 are supported by multidisciplinary healthcare teams, who provide accurate and balanced information, facilitate shared decision-making, and promote access to quality clinical care. To realize this vision, the Collaborative partners with health systems, educational institutions, professional societies, and patient advocacy organizations to:

- Promote research and education about trisomy 13 and 18
- Disseminate knowledge to healthcare teams and families
- Improve health care teams’ capacity to care for children and families, spanning the prenatal period through adulthood

The Collaborative is a philanthropic initiative of the New Venture Fund (NVF), a US-based, 501(c)(3) public charity, established in 2024.

The Collaborative’s scientific leadership team is Tesla N. Theoryn MEd and Benjamin S. Wilfond MD. They are supported by a 22-person multidisciplinary steering committee that plays a vital role in shaping a strategy to advance the Collaborative’s vision for the future.

Additional information about the Collaborative and previously funded projects can be found on the Trisomy Collaborative website: <https://trisomycollaborative.org/projects>

OPPORTUNITY

The Collaborative will issue awards of up to \$250,000 for one-year projects or \$500,000 for two-year projects to research teams affiliated with a university, academic medical center, or non-profit organization based in the United States or Canada. These teams will serve as research partners to carry out a broad range of projects aimed at improving clinical care and family experiences.

Through these awards, the Collaborative seeks to better understand and improve patient-clinician relationships, clinical care and outcomes, and navigation of the medical system for families impacted by trisomy 13 and 18. Research findings will inform future efforts to develop guidelines for clinical care, clinician training programs, and family resources.

To help applicants better understand the range of projects that may be supported, the Trisomy Collaborative has identified examples of topics and themes that could be important for improving clinical care and experiences for families impacted by trisomy 13 or 18. These concepts were generated during strategic sessions focused on needed research to improve care. Notably, applicants need not feel limited to these topics or themes in their proposals, as selection criteria are focused more broadly on the capacity of a project to advance clinical care and family experiences:

1. Understanding common clinical problems, interventions, and clinical outcomes.
2. Developing care pathways that meet the needs of families, from prenatal pathways to transitions to adult care, and everything in between.
3. Understanding clinician experiences and/or addressing potential clinician disability bias.
4. Facilitating clinician-patient communication, spanning from those involved in initial family communication such as obstetricians, genetic counselors, and neonatologists, to those with ongoing relationships, such as primary care, complex care, or palliative care clinicians.
5. Development of stories/narratives that can improve clinical care or family experience, including stories of families or clinicians.
6. Understanding regional differences in clinical service availability and/or the reproductive policy environment and their impact on care.
7. Enhancing family navigation of healthcare and social environments.

METHODOLOGIES

An array of research methodologies will be considered, including qualitative and quantitative approaches, hypothesis-generating and descriptive studies, and research grounded in implementation and dissemination science, provided the work aligns with the overarching objective of improving clinical care and family experiences. Community-engaged research approaches are strongly encouraged.

REPRESENTATION

The Collaborative recognizes the variability of family and clinician experiences based on available care choices, chosen care pathways, socioeconomic, demographics and cultural factors, and involved care teams. As appropriate, projects should consider variation between and representation of these factors.

In some proposals, it may be appropriate to focus on experiences in specific populations or contexts (e.g., obstetrics communication strategies). In others; proposals may call for a broader, or comparative approach. In either case, it is important to justify the chosen focus, demonstrating an understanding of the complex landscape of care and experiences.

DELIVERABLES AND ENGAGEMENT

Deliverables and engagement will include:

1. A presentation of interim project progress at the Collaborative Annual Conference (typically in the spring).
2. A publishable report on the project findings.
3. A final report of the results of the research for internal use by the Collaborative.
4. A finalized product for dissemination, if applicable (e.g. a clinician training course or family navigation resource)
5. The Collaborative's scientific leadership team is available to provide input on and respond to questions about these projects as they progress. To facilitate this partnership, the selected applicants can meet with the Collaborative regularly depending on their needs.

SELECTION CRITERIA

The primary criteria for project selection is a relevant question that, when answered, has the potential to advance clinical care and family experiences for families impacted by trisomy 13 or 18.

Further, successful applicants will demonstrate:

- Experience and capability to conduct the type of project proposed.
- Knowledge and experience regarding children with medical complexity or genetic disorders.
- A strong and feasible methodology and an ability to carry out the project
- Strong alignment with the Collaborative's mission and vision.
- A commitment to making research findings accessible to relevant stakeholders.
- A commitment to collaborating with the Collaborative, including its staff and steering committee.
- The ability to complete the work on time and within budget.

APPLICATION PROCESS

The Collaborative is committed to being clear and transparent about the application and selection process. Throughout the process, applicants are welcome to email questions to Ben Wilfond or Tesla Theoryn via email: wilfond@trisomycollaborative.org, theoryn@trisomycollaborative.org

TIMELINE

Date	Process Step
JUNE 1	Request for Proposals Released
June 3	Applicant Webinar(s)
JULY 10	LOI Submission Deadline
AUGUST 21	Subset of Applicants Invited to Develop Proposals
OCTOBER 16	Proposal Submission Deadline
NOVEMBER 23	Applicants Informed of Award Decision
JANUARY 1, 2027	Anticipated Award Start Date

PROCESS

1. The Trisomy 13 and 18 Collaborative will **host an informational webinar on June 3 at 3:00 pm ET / 12:00 pm PT**, on the Trisomy Roundtable platform. Interested applicants are encouraged to sign up to join the Roundtable at: roundtable.trisomycollaborative.org. Roundtable members can view the recorded meeting at: <https://roundtable.trisomycollaborative.org/c/past-meetings/>
2. Interested applicants are invited to **submit a Letter of Intent (LOI)** to the Trisomy 13 and 18 Collaborative by July 10th to share their interest in this funding opportunity. The information requested in the LOI is on page 5.
3. **By August 21st, a subset of LOI applicants will be invited to submit a full proposal.**
4. **The proposal submission deadline is October 16th.** All proposals should be submitted via email to Trisomycollaborative@newventurefund.org.
5. **Applicants will be notified of final funding decisions by Monday, November 23rd.** Should the timeline change, the Trisomy Collaborative team will be in touch with applicants. We anticipate issuing approximately eight awards, roughly four 1-year awards and four 2-year awards.

This invitation does not oblige the New Venture Fund to pay any costs incurred by applicants in the preparation and submission of a proposal. Furthermore, the invitation does not oblige the New Venture Fund to accept or provide funding for any expressed or implied services.

LETTER OF INTENT REQUIREMENTS

Applicants are invited to submit an LOI and the following information via email as a single PDF to Trisomycollaborative@newventurefund.org.

1. A cover page, including:
 - a. Proposal Title
 - b. Principal Investigator (and email)
 - c. Institution
 - d. Authorizing Institutional official (and email)
 - e. Proposal Summary (3-4 sentences)
 - f. Total funding Request
 - g. Start and End Dates of the Proposed Project. Please assume a January 1, 2027 start date.
 - h. How you heard about the RFP
 - i. A response to the following question, as required by the New Venture Fund, the project's fiscal sponsor: Will any part of this grant funding be used to conduct lobbying as defined by federal tax law?¹
2. A Project Plan that does not exceed two pages, single spaced, formatted in Arial, size 11 font that addresses the five topics listed here (citations not included in the 2-page limit):
 - a. **Objective:** Describe the research question and rationale, as well as the specific aim(s) of the research project.
 - b. **Approach:** Describe the methodology you will use to achieve the aims, and the anticipated dissemination products.
 - c. **Team:** Identify the team members contributing to the project, highlighting their relevant experience and expertise.
 - d. **Timeline:** Describe the proposed timeline for completing the research. Please assume a grant start date of January 1, 2027. If you anticipate any challenges in meeting this timeline or if you anticipate completing the research in less than 12 months, please provide an explanation.
 - e. **Estimated total costs:** Provide an estimated total project cost. If you anticipate challenges in meeting the budget parameters listed below, please explain. Funding is available for the following grant terms. Please note that up to 10% can be allocated to indirect costs:
 - i. One-year award: January 1, 2027 – December 31, 2028, up to \$250k, if justified.
 - ii. Two-year award: January 1, 2027 – December 31, 2029, up to \$500k (250k per year), if justified.

LOIs should be submitted via email to Trisomycollaborative@newventurefund.org by July 10th at 11:59 PM EST. Applications that do not respond to all LOI prompts or are not received by the deadline will not be considered. Applicants will receive a confirmation email upon receipt of their LOI. The Collaborative will review LOIs and select applicants to submit a full proposal. **The next section is for informational purposes only. The Collaborative will contact those invited to submit a full proposal in August 2026.**

¹ As a fiscally sponsored project of New Venture Fund, a 501c3 public charity, Trisomy 13 and 18 Collaborative is currently prohibited from funding any lobbying or political or activity.

PROPOSAL REQUIREMENTS

A subset of those who submit an LOI will be invited to submit a proposal. These applicants will receive additional instructions for submitting a proposal and accompanying materials via email. **The deadline for submitting a proposal, if invited, is October 16th at 11:59 PM PST.**

To submit a proposal, applicants must submit the following via email:

1. Cover Page (see LOI requirements)
2. A proposal that does not exceed six pages in length, formatted in Arial, size 11 that addresses the topics listed here:
 - a. **Objective:** Describe the research question and specific aim(s) of the research project.
 - b. **Background:** Provide the relevant context for the research and justify the significance and need for the proposed project.
 - c. **Approach:** Your expected approach to conducting this research, including background, preliminary work, methodology, and how you will ensure you will address the question rigorously.
 - d. **Risks:** Describe key risks or challenges that could compromise this project and plans to mitigate these risks.
 - e. **Timeline:** Provide a detailed timeline, including major milestones and your anticipated final work products.
3. A complete **budget and budget justification:**
 - o **Budget:** Applicants must submit a detailed project budget using the provided template.
 - The institution may allocate up to 10% of the total budget for indirect costs
 - The budget should include potential open access publications fees and travel for dissemination presentations. Travel to the Collaborative Annual Conference should not be included.
 - o **Budget Justification:** A budget narrative must accompany the application, providing a detailed cost justification. The narrative should describe each team member's role on the project and their expected level of effort; and provide an explanation of all proposed expenses.
4. **A biosketch for each key personnel**, in the NIH format (up to 5 pages), including education, professional experience, contributions to science, and selected peer-reviewed publications. The biosketch should follow the 2025 NIH guidelines for non-fellowship awards (not SciENCv), which can be found [here](#).

Please note: The following requirements will only be requested from selected finalists — there is no need to submit them at this stage. Once notified in late-November, finalists will have 1–2 weeks to provide the necessary materials in order to allow for grant disbursement by the end of year. We are sharing these requirements now for your awareness, to help expedite the process later in the timeline.

- Organization website (if applicable).
- Proof of legal status, such as a Form W-9, Form W-8 BEN-E, Letter of Determination, etc. (If you have an equivalency determination letter, please provide.)
- Payment information using the attached EFT Form (If in Canada, please use Wire Form).
- Most recent IRS Form 990. If you do not have a 990, please upload a document indicating why you do not have a 990. This may simply be a sentence or two. (If in Canada, please fill out the international Applicant Financial Overview Form).
- If you are a Canada based applicant, the international applicant financial overview form.
- Most recent audited financials. If your organization does not have an audit, please upload a document indicating why not. This may simply be a sentence or two.
- An organization budget (this is only a requirement if the applicant is **not from** a university/academic medical center).
- A list of your organizations' key staff and board of directors if not included in your 990.

If invited, proposals and accompanying information should be submitted by October 16th at 11:59 PM PST. Applications that are not received by the deadline will not be considered. Applicants will receive a confirmation email upon receipt of their proposal.